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ABSTRACT

An overview is presented on current knowledge about elderly mentally retarded persons. Definitional and incidence issues are addressed, and support is voiced for use of a lower cut-off for the beginning of old age among the retarded than for the general population. Conflicting findings of age-related differences in mentally retarded adults are considered. Friendship and behavior patterns among elderly mentally retarded persons (compared to the nonretarded elderly) are viewed as important research topics. The service needs of the older mentally retarded population are noted, including residential services, alternative day placements, legal protection and financial management. Efforts currently underway to survey nationwide services available to elderly mentally retarded clients are briefly reviewed. (CL)

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Older Mentally Retarded Persons: Demographic Profile and Service Requirements

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Interest in aging mentally retarded persons has grown considerably during the past few years, as gerontologists and mental retardation specialists have recognized the size of this group and speculated about its unique needs (Janicki & MacEachron, 1984; Puccio, Janicki, Otis, & Rettig, 1983; Seltzer & Seltzer, in press; Seltzer, Seltzer & Sherwood, 1982). My purpose today is to present an overview of current knowledge about elderly mentally retarded persons, with specific reference to four questions:

1) What is the best definition of old age in the population of mentally retarded persons and how many mentally retarded persons can be classified as elderly?

2) To what extent do elderly mentally retarded persons differ from younger retarded adults?

3) To what extent do elderly mentally retarded persons differ from the general (i.e., non-retarded) elderly population?

4) What are the service needs of elderly mentally retarded persons and what services are currently available for them?

Given the breadth of these issues, it will only be possible to address each briefly. However, I have extra copies of the bibliography of my paper should any of you be interested in exploring these issues in greater depth.

What is the best definition of old age in the population of mentally retarded persons and how many persons can be classified as elderly?

In past research on aging and mental retardation, the onset of old age has been defined demographically (age in years). No studies have been conducted of the mentally retarded population which utilize functional, psychological, or social definitions of aging, although such definitions have been conceptualized for the general elderly population (Birren, 1959; Eisdorfer, 1983; Siegel, 1980). In past research on mentally retarded persons, various ages have been used as the lower limit of old age, including age 50 (Baker, Seltzer, & Seltzer, 1977; Talkington & Chiovaro, 1969), age 55 (Neuman, 1981; Segal, 1977; Seltzer et al, 1982), and age 60 (O'Connor, Justice, & Warren, 1970). Two recent studies, (Janicki & MacEachron, 1984; Sutton, 1983) distinguished among those in late middle age (ages 53-62), the aging (ages (63-72), and the aged (ages 73 and older).

Substantiation for the use of a lower cut-off for the beginning of old age among mentally retarded persons than for the general population is provided by evidence that 1) mentally retarded persons begin to decline in behavioral capacities during their 50's (Puccio et al 1983), 2) there is an increased incidence and earlier onset of Alzheimer's Disease among persons with Down Syndrome (Lott & Lai, 1982; Miniszek, 1983), and 3) retarded persons have a shorter average lifespan than the general population (Janicki & MacEachron, 1984; Tarjan, Wright, Eyman & Keeran, 1973).

It is commonly noted that there are two sub-groups of the mental retardation population: those who are without additional physical handicaps and who are most often mildly retarded, and those who have some organic basis for their retardation and who generally are more severely retarded and have multiple handicaps (Grossman, 1983). The life expectancy and aging process for these two groups probably differs substantially, further complicating the

definition of old age for mentally retarded persons.

In my current research on aging and mental retardation the lower limit of old age has been set (somewhat arbitrarily) at age 55. A longitudinal study of the aging process in the MR population would help to validate this demarkation point.

Estimates of the number of elderly mentally retarded persons in the United States are generally based on samples of service recipients, and thus undoubtedly are underestimates. To illustrate this point, in Robert Edgerton's most recent follow-up study of the deinstitutionalized subjects he has followed since the 1960's (Edgerton, Bollinger, & Herr, 1984), not a single one of the sample of 15 (all but one of whom were over age 50) was receiving any service from the formal mental retardation service network. Thus all of these subjects would likely have been omitted from surveys attempting to estimate the prevalence of old age in the served MR population.

Rough indications of the current size of this population can be derived by applying estimates of the prevalence of mental retardation to the number of persons over the age of 55 in the United States identified in the 1980 census. The American Association on Mental Deficiency has estimated that approximately 3% of the population is mentally retarded. However, many have argued that the 3% prevalence estimate is unrealistically high and instead posit that only 1% of the population is truly retarded (Mercer, 1973). For elderly retarded persons it is possible that even the 1% rate might overestimate the size of this group due to their shorter average lifespan. Applying the 1% prevalence estimate to the 1980 census data yields a population size of 460,000 mentally retarded persons over the age of 55.

To what extent do elderly MR persons differ from younger MR adults?

A number of authors have asserted that elderly mentally retarded persons have needs that are different from those of younger retarded adults (Anglin, 1981; DiGiovanni, 1978; Segal, 1977; Sweeney, 1979). This argument is consistent with the accumulated evidence in the field of gerontology regarding age-related differences characteristic of the non-retarded elderly population, namely that with increasing age, the health, functional abilities, and availability of informal supports of the general elderly population have been found to significantly decline (Kart, Metress & Metress, 1978; Lowenthal & Robinson, 1976; Neugarten, 1982).

The extent to which these age-related differences are characteristic of mentally retarded persons has been directly examined in only a few studies, which have produced conflicting findings. While Edgerton et al (1984), based on a longitudinal study, reported an improved quality of life associated with advancing age, other studies have found a mixed pattern of differences between adult and elderly mentally retarded persons. For example, Janicki and MacEachron (1984), in a cross-sectional design, analyzed data from a statewide needs assessment in New York state. They reported that elderly mentally retarded persons were more likely to live in institutional settings, were less likely to be involved in a day activity, were more likely to receive specialized medical services, and were more likely to have unmet service needs in such areas as physical and occupational therapy and recreational activities than their younger mentally retarded adult counterparts.

In another cross-sectional study, Krauss and Seltzer (1984) compared four cohorts of mentally retarded persons who received state-supported services: 1) those aged 22-30, 2) those aged 31-54, 3) those aged 55-74, and 4) those aged 75 and older. As expected, it was found that there was a positive linear

relationship between medical problems and age, with 85% of those over the age of 75 having a significant medical condition as compared with 55% of the youngest group. Functional abilities were found to be curvilinearly related to age, with the young adults aged 22 to 30 and those over the age of 75 having the lowest scores, and those between the ages of 55 and 74 having the highest scores. Somewhat unexpectedly, level of mental retardation was linearly but inversely related to age, with the oldest group found to be least severely retarded.

Changes in the eligibility criteria for state-supported mental retardation services which have occurred during this century may explain why the older age groups were found to be less severely retarded. As Scheerenberger (1982) reported, the average severity of retardation of persons admitted to state schools has increased considerably during this century. Consequently, older cohorts in institutions contain a larger proportion of mildly retarded persons than do younger institutional-based cohorts. This is also true of community residences, which contain many formerly institutionalized persons. Furthermore, given the shorter lifespan characteristic of severely and profoundly retarded persons (Janicki & Wisniewski, in press; Rotegard, Bruininks, & Lakin, 1982), younger cohorts include individuals who are not expected to survive to old age and who thus depress the average level of retardation score in their groups. Consequently, the better cognitive abilities characteristic of the older groups can be attributed to between-cohort differences rather than to intra-individual cognitive improvement over time.

Further research, preferably utilizing a longitudinal design, is needed to determine the magnitude and nature of age-related differences in this population. For planning purposes, this knowledge would be useful in assessing the need for age-specialized versus age-integrated mental

retardation services. Small differences between younger adults and elderly mentally retarded persons would argue for age-integrated MR services whereas larger differences would argue for age-specialized MR services.

To what extent do elderly MR persons differ from the general (i.e., non-retarded) elderly population?

A related issue pertains to the feasibility of including aging mentally retarded persons in services designed for the non-disabled elderly population. While Dybwad (1962) raised this issue over 20 years ago, only a few studies have been conducted to assess the degree of difference between these two groups.

Callison et al (1971) compared elderly mentally retarded, elderly schizophrenic, and elderly non-disabled persons with respect to over-time changes in their visual ability, hearing, and grip strength. All groups were found to deteriorate over time in these three areas. However, among the three groups, the mentally retarded elderly deteriorated the most in vision and hearing. Thus, with respect to sensory abilities, it may be that the combination of advanced age and mental retardation poses special problems. Sherwood and Morris (1983) also studied mentally retarded, mentally ill, and elderly persons in an evaluation of the Pennsylvania Domiciliary Care Program. Each of these client groups was compared with its own matched control group which did not reside in domiciliary care homes. The three client groups were found to respond similarly to placement in a domiciliary care home in many respects with the exception that the mentally retarded clients deteriorated in functional abilities over time while the other two groups did not. Cotton, Sison, & Starr (1981) compared elderly mentally retarded residents of a public retardation facility with non-retarded elderly residents of an ICF, and non-retarded elderly persons who lived in the

retarded persons, given their more limited network of relatives. Edgerton (1967) conceptualized and documented the role played by "benefactors" in the lives of the formerly institutionalized adults he studied. Were it not for these benefactors, many of the study group would have been at risk for re-institutionalization.

Other research has focused on the availability and role of friends among mentally retarded adults. While a number of studies have documented the fact that mentally retarded persons do have friends (Gollay, Freedman, Wyngaarden & Kurtz, 1978; Intagiata, Crosby & Neider, 1981; MacAndrew & Edgerton, 1966; O'Connor, 1976; Scheerenberger & Felsenthal, 1976), much less is known about the qualitative such aspects of friendships. Landesman-Dwyer and her colleagues conducted two studies in which the characteristics of friendship patterns among mentally retarded adults in group homes were analyzed (Landesman-Dwyer, Berkson, & Romer, 1979; Landesman-Dwyer, Sackett, & Kleinman, 1980). They found that there was significantly less overall social behavior in group homes with older residents than in group homes with younger adult residents and that friendships were most likely to be formed between people who were similar to one another in age.

An analysis of the degree of similarity between the informal support network of elderly retarded and elderly non-disabled persons is a particularly important area for future research, given the central role close friends and families have been found to play in the prevention or delay of institutionalization for the general elderly population.

What are the service needs of aging mentally retarded persons and what services are currently available for them?

Janicki and his colleagues in New York State have conducted several analyses of the service needs of elderly mentally retarded persons (Janicki,

Otis, Puccio, Rettig, & Jacobson, in press; Janicki & MacEachron, 1984; Puccio et al, 1983). In addition to escalating health care needs, perhaps the major service need for this group is in the residential domain. More than 50% of the aging retarded persons who receive state supported services in New York live in institutional settings (Janicki & MacEachron, 1984), a situation also characteristic of aging mentally retarded persons in Massachusetts (Krauss & Seltzer, 1984). This is in sharp contrast to the commonly cited fact that only 5% of the general elderly population reside in institutional settings at any one time. There is thus a need to examine the feasibility of including elderly mentally retarded persons in community-based residential programs.

Very few aging retarded persons live their with elderly parents. Their service needs include in-home support for both the retarded individual and his/her parent, physical modification of the home, anticipatory planning for the future, and pre-crisis placement (Janicki et al, 1984).

Another major service need pertains to alternative day placements. The issue of retirement from vocationally-oriented day placements needs to be addressed on both a practice and policy level. Janicki et al (1984) pointed out that alternative types of day placements should emphasize productive use of leisure tme, the maintenance of self-care skills, and support for continued social contacts.

Other areas of service need for elderly mentally retarded persons include legal protection and financial management (Seltzer & Seltzer, in press). Case management might be a particularly useful service for this client group, as their needs are intensive and because the resources to meet these needs must be accessed from two discrete service networks (MR and aging). However, very few professionals have expertise with both populations and thus there is a need for staff training to help case managers and others effectively serve this emerging client group.

Apart from these very general statements about service needs, little is known about either the services currently available for elderly mentally retarded persons or precisely defined areas of unmet need. In order to collect basic descriptive information about services for this group, Dr. Marty Krauss of Brandeis University and I have been funded to conduct a nationwide study of services currently in existence for elderly mentally retarded persons. We are in the process of identifying programs nationwide in which at least 50% of the mentally retarded clients are aged 55 or older. To assemble this list, we have published descriptions of our study in about one dozen newsletters, and have sent large mailings to the following groups:

1) state programs directors in each of the 50 states for mental retardation, aging, and mental health;

2) all state and local units of the US Association for Retarded Citizens;

3) all public institutions for mentally retarded persons in the U.S.; and

4) individual programs that were identified as possibly serving elderly mentally retarded persons.

To date, 193 programs have been identified which meet our inclusion criterion. These programs can be roughly categorized as follows:

	n	%
Residential	72	37.3
Day	47	24.4
Social/recreational	47	24.4
Misc. supportive	27	13.9
	193	100.0

Our plan is to conduct in-depth telephone interviews with each of those programs during the next few months. The interview schedule, which is currently nearing is final form, covers the following domains:

1. History of the program
2. Client characteristics
   a. demographics
   b. disabilities & health
   c. services recieved
3. Program sponsorship and funding
4. Physical setting of the program
5. Staffing pattern
6. Special program characteristics, feature, or problems related to serving elderly MR persons

Our goals are:

1. to develop a typology of programs;
2. to compare the services provided to elderly MR persons and the other clients who are served; and
3. to compare the services provided in community-based settings with those provided in institutional settings.

I have a description of our study for those who are interested and a form for identifying programs for those who are familiar with a program that meets our criteria (over 50% aged 55 or older). We hope to hear from you. Thank you very much.

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